



H.R. 493 - Genetic Information Nondiscrimination Act of 2007

Floor Situation

H.R. 493 is being considered on the floor under suspension of the rules and will require a two-thirds majority vote for passage. This legislation was introduced by Rep. Slaughter (D-NY) on January 16, 2007. The bill was ordered to be reported from the Committees on Education and Labor, Energy and Commerce, and Ways and Means.

H.R. 493 is expected to be considered on the floor on April 27, 2007.

**Note: Similar legislation, S.358, was introduced in the Senate, which is sponsored by Senator Snowe (R-ME). It was referred to the Senate Health, Education, Labor and Pensions (HELP), which ordered the bill to be reported. The full Senate has not taken action on this bill.*

Summary

The purpose of H.R. 493 is to prevent genetic discrimination in health insurance and the workplace, by prohibiting insurers from basing premium and coverage decisions on genetic information, as well as forbidding employers from hiring or firing individuals based on the same information. H.R. 493 has three titles: the first two detail the major elements of the legislation regarding health insurance (Title I) and employment provisions (Title II). Title III of GINA is a severability provision. Specifically this legislation would:

- Amend the Employee Retirement Income Security Act of 1974 (ERISA) and the Public Health Service Act to set penalties for health plans and insurers who discriminate in enrollment and premiums based on genetic information, as well as banning them from requiring genetic testing.

**Note: This strengthens the prohibition against discrimination by group health plans and health issuers in the group and individual markets on the basis of genetic information or services to prohibit genetic discrimination.*

- Amend title XVIII (Medicare) of the Social Security Act to prohibit issuers of Medicare supplemental policies from discriminating on the basis of genetic information.

**Note: Currently Medicare does not include language specifically prohibiting genetic discrimination.*

- Ban a group health plan, a health insurance issuer, or issuer of a Medicare supplemental policy from using or disclosing genetic information (including information about a request for or a receipt of genetic services by an individual or family member of such individual) for purposes of underwriting, determinations of eligibility to enroll, premium rating, or the creation, renewal or replacement of a plan, contract or coverage for health insurance or health benefits.

**Note: This is more restrictive than HIPAA because it extends medical privacy and confidentiality rules to the disclosure of genetic information and prohibits health plans from acquiring such information.*

- Bans employers, employment agencies, labor organizations, or training programs from discriminating against or depriving an individual of employment opportunities based on genetic information.
- Forbid the collection and disclosure of genetic information, with certain exceptions.
- Extend genetic information protections to fetus' in the case of woman who is pregnant.
- Establish a Genetic Nondiscrimination Study Commission to review the developing science of genetics and advise Congress on the impact of this Act.

**Note: The purpose of this commission is to evaluate for any disparate impact that has resulted from this legislation.*

- Require employers to keep genetic information separate from other employee health information;
- Establishes that if any provision of this Act, an amendment made by this Act, or the application of such provision or amendment to any person or circumstance is held to be unconstitutional, the remainder of this Act, the amendments made by this Act, and the application of such provisions to any person or circumstance shall not be affected thereby.

**Note: This is known as Severability.*

Background

The human genome is made up of an individual's DNA; containing genes, which are packaged in chromosomes and affect specific characteristics. Research into the human genome has resulted in a wealth of information such as specific genes that are linked to

diseases such as Alzheimer's or Cancer. Further, studies of the human genome have led to the development of tests to determine an individual's likelihood to have certain genetic diseases. Overall, understanding an individual's genetic makeup can lead to early detection and prevention of disease.

While genetic information can be paramount in research and development, information regarding an individual's genetic makeup may also be used to against them. Specifically this type of information can be used by health insurers and employers to discriminate against those who are known to –or have the potential to- carry genes that increase their likelihood for developing cancer or other chronic diseases. This may cause individuals who have the hereditary potential of inheriting a disease to refrain from genetic testing, in order to keep their insurance; which could lead to even higher health costs, and deaths in the future due too genetic illnesses that could have been easily treated. Further, genetic discrimination could lead to a decrease in innovation and research do to a lack of participation.

Cost

“CBO estimates that enacting H.R. 493 would reduce revenues by less than \$500,000 in each year from 2008 through 2017, by \$1 million over the 2008-2012 period, and by \$2 million over the 2008-2017 period. (These estimates include reductions in off-budget receipts from Social Security payroll taxes of less than \$500,000 over the 2008-2012 period, and slightly less than \$1 million over the 2008-2017 period.) The bill's requirements would apply to Medicare supplemental insurance, which could affect direct spending for Medicare. However, we estimate that the bill would have no significant effect on direct spending.” Congressional Budget Office
<http://www.cbo.gov/ftpdocs/80xx/doc8001/hr493.pdf>

Staff Contact

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